

# Nurturing Relationships:

Updates from the JHU/NHGRI Genetic Counseling Training Program

*Welcome to the spring edition of the Johns Hopkins University/National Human Genome Research Institute Genetic Counseling Training Program Newsletter. This newsletter is intended for individuals affiliated with the program, including faculty, clinical supervisors, alumni, support staff, Executive Committee members and current and prospective students. We hope it will keep you up-to-date about our program.*

## Program Updates

We bid a sad farewell to our retiring Executive Committee Members: Kim Kaphingst, ScD, Trish Magyari, MS, MA, and Rajiv Rimal, PhD. Executive Committee members serve an invaluable role in the GCTP. They are the Admissions Committee, they guide students in their research as thesis and faculty advisors, and they provide oversight and direction to the GCTP. We are extremely grateful to these departing members, as well as the members who remain on the committee, for their years of service and dedication to the program.



Lori Leonard, ScD

We are fortunate to be welcoming a new Executive Committee member, Lori Leonard, ScD, Associate Professor, Johns Hopkins Bloomberg School of Public Health Department of Health, Behavior and Society. Dr. Leonard's current research includes two primary projects. The first involves a multi-disciplinary, international team of researchers and is a long-term study of the impacts of the development of the oil industry and the construction of a major pipeline on households in southern Chad. The second is project is an ethnographic study of the social worlds of young women in four major US cities who are living with HIV. We welcome Dr. Leonard's future contributions.



Susan Richardson

We're pleased to announce that Kathryn Foisie, GCTP Program Coordinator at NIH, gave birth to a healthy baby boy on November 19, 2009. His name is Hudson Foisie and with his arrival, Kathryn accepted the position of full time parent. We're sad to see her leave, but welcome Susan Richardson as the new GCTP Program Coordinator at NIH.

## Class of 2010

On January 22, 2010 in the Cloisters Building at NIH we celebrated the graduation of Morgan Butrick, Amanda Lamb, Amanda Singleton and Amy Turriff from the GCTP. It was, as always, a bittersweet ceremony. It is sad to say goodbye to daily interactions with these individuals. However, we are pleased to have four new colleagues in the field, many of whom are staying in the area.

### Theses studies

**The Roles of Trust & Respect in Patient Reactions to Race-based & Personalized Medicine Vignettes: an Experimental Study**  
Morgan Butrick, Sc.M. Advisor: Debra Roter, DrPH, MPH

**The Role of Family Functioning in Adaptation to Being a Caregiver of an Individual with Rett Syndrome**  
Amanda Lamb, Sc.M. Advisor: Lori Erby, PhD

**Informed choice and persuasion in direct-to-consumer genetic testing (DTCGT) websites**  
Amanda Singleton, MPH, Sc.M. Advisor: Kim Kaphingst, ScD

**Adaptation among Adolescents and Adults with Klinefelter Syndrome**  
Amy Turriff, Sc.M. Advisor: Barbara Biesecker, MS

## Where are they now?

**Morgan Butrick** has enjoyed down time in Baltimore while she looks for permanent employment. She's preparing her thesis for publication and continuing to work with her advisor, Debra Roter, on a communication meta-analysis. She's also enjoyed traveling, brushing up her Spanish, and spending time with family and friends.

**Amanda Lamb** is covering Jennifer Sloan's maternity leave at NHGRI, working on a natural history study of methylmalonic acidemia and related disorders. Amanda and her husband, Colin, will be relocating to Maine this summer. Amanda was recently hired at Maine Medical Center at the Cancer Risk and Prevention Clinic and Colin will begin a residency program in pediatric psychiatry.

**Amanda Singleton** has been enjoying staying at home with her daughters Emily (8yrs) and Olivia (4yrs). She and her family will be relocating from Silver Spring, MD, to Poolesville, MD in June. Her goal is to obtain a position in Frederick or Gaithersburg when Olivia starts kindergarten in the fall.

**Amy Turriff** was thrilled to accept a genetic counseling position at the National Eye Institute (NEI). Amy works with **Delphine Blain ('04)** and is involved with the X-linked retinoschisis and Usher syndrome research protocols. She provides genetic counseling to pediatric and adult patients seen in the clinic.



(photo: Bill Branson, NHGRI)

GCTP Class of 2010: (Left to right) Amanda (Rowe) Lamb, Amanda Singleton, Morgan Butrick, Amy Turriff

## Alumni Research Symposium



(photo: Bill Branson, NHGRI)

Shawn (Sineski) Lipinsky ('04) and Kira (Apse) Dies ('03) talk during a Symposium break.

On January 29, 2010, the GCTP hosted an Alumni Research Symposium on the NIH campus in Bethesda. The goal of this symposium was to bring alumni together to share research results, brainstorm future projects and establish connections across alumni. The symposium was the single largest gathering of GCTP alumni since the program's inception and included almost 40 alumni as well as current students and past and present faculty members.



(photo: Bill Branson, NHGRI)

Tricia (Gasser) See ('05) leads a networking session.

The day began with research presentations from **Robin (Cohen) Hayeems, ScM, PhD ('01)**, **Kira (Apse) Dies, ScM ('03)** and **Lori Hamby Erby, ScM, PhD ('00)**. Barbara Biesecker, MS gave a preview to a systematic literature review of studies evaluating the process and outcome of genetic counseling toward evidence-based practice. Perhaps the most exciting discussions were the afternoon networking sessions where attendees described their current research, shared ideas for future projects, identified implementation barriers and got feedback from colleagues. One outcome of this symposium was the establishment of a Google group to foster further exchange and collaboration. For those alumni unable to attend but who are interested in research, please send Barb an email expressing your desire to join the group.

## A Word From One Of The GCTP Supervisors

Beth Wood Denne, genetic counselor at Johns Hopkins Hospital, recently offered to describe her trip to a Johns Hopkins affiliate hospital in Abu Dhabi. If you're interested in submitting

an article for Nurturing Relationships, send Barb or Anne an email. Our contact information is at the end of the newsletter.

### A Visit to Abu Dhabi, UAE

by Beth Wood Denne, MS, CGC, Johns Hopkins Hospital

Shortly after ringing in 2010, I found myself flying 7,000 miles from Washington, DC to Dubai, United Arab Emirates. I touched down in Dubai the same day that the city was celebrating the grand opening of the world's tallest building, the Burj Khalifa (2,717 feet). I enjoyed the view of this grand structure as my driver made his way out of the city for the 60-minute drive to Abu Dhabi.



Beth Wood Denne, MS

Al Corniche Hospital is a Johns Hopkins affiliate located in Abu Dhabi. I was fortunate to visit this hospital for one-week with a JHU Maternal-Fetal Medicine physician.

Al Corniche is an all-women's hospital providing Gynecologic and Obstetric services to the majority of women in the UAE; they deliver over 11,000 babies each year.

I spoke at sessions similar to our Grand Rounds about the genetic counseling implications of abnormal ultrasound findings to an audience that included physicians, nurses, and other hospital staff. I was also able to participate in several case conferences and facilitated workshops on how to discuss difficult issues and how to give bad news. I found that despite cultural differences, the main themes and concepts related to giving bad news are no different in the US than in the UAE.

The ethnicities of their patient population include Emirati, Arab, and Persian as well as women from many other origins. While the majority of women seen at Al Corniche are Muslim, other religions including Christianity, Hindu, and Sikh are also represented. I was surprised to see a wide variety of head-covering practices, from no covering to full face-covering burqas. This variation is because a woman's dress is determined by her individual or family beliefs, not by the state. Al Corniche is introducing the concept of men being present for the birth of their children, which is quite progressive for a culture in which men and women are often separated in public spaces. The hospital has made culturally sensitive accommodations including separate waiting areas, clinic spaces, and patient rooms

for women there with male partners and women there alone or with female relatives.

Dr. Gowri is the hospital's only fetal medicine specialist (the equivalent of an MFM in the US). With no genetic counselors, he personally scans and counsels all patients with abnormal ultrasound findings. The physicians do very few prenatal diagnostic tests. The few patients who elect to terminate a pregnancy leave the country to obtain the procedure. With over 50% consanguinity among the patient population, the presenting problems are often the result of autosomal recessive conditions. When there is funding, Dr. Gowri hopes to hire a genetic counselor at Al Corniche.

## Alumni News



Leo Cua See, son of Tricia and Kevin See.

**Tricia (Gasser) See ('04)** delivered a son, Leo Cua See, on April 17, 2010. Leo and Tricia are both doing well.

**Julie Chevalier Sapp ('04)** is pleased to report the publication of her thesis research: Sapp JC, Hull SC, Duffer S, Zornetzer S, Sutton E, Marteau TM, Biesecker BB. Ambivalence toward undergoing prenatal testing: an exploration of its origins. *Prenat Diagn* 2010 Jan;20(1):77-82.



Alissa Bovee Terry ('06) and her son, Fletcher.

**Alissa Bovee Terry ('06)** gave birth to a baby boy, Fletcher Jackson Terry, on November 24, 2009. She reports that he is growing fast and doing lots of smiling and laughing these days. She and her family have lived in Stamford, CT for 2½ years and she is currently taking a break from her position at the Ferre Institute in Binghamton, NY, so that she can spend time with Fletcher.

**Julie Cohen ('09)** shares the news of her recent publication: Cohen JS, Biesecker BB. 2010. Quality of life in rare genetic conditions: A systematic review of the literature. *Am J Med Genet Part A* 152A:1136-1156.

We invite you to continue sharing your personal and professional news with us so that we can update the GCTP community. Anne can be reached at [Anne.Madeo@nih.gov](mailto:Anne.Madeo@nih.gov) and Barb can be reached at [barbarab@mail.nih.gov](mailto:barbarab@mail.nih.gov).